

A photograph of a man and a young girl sitting at a desk. The man is holding a tablet, and the girl is leaning over his shoulder, looking at the screen. On the desk, there is a laptop, some papers, and a green marker. The background is slightly blurred, showing a kitchen area.

# The Power of Evidence: Rosalynn Carter Institute Impact on Caregivers in America

Rosalynn Carter Institute  
For Caregivers





"There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers."

– Former First Lady Rosalynn Carter

# Why We Are:

## Experience with Courage and Visionary Leadership



Rosalynn Carter Institute was founded with the mission to carry on Former First Lady Rosalynn Carter's visionary leadership to ensure family caregivers are seen, heard, and supported. Her personal experience—caring for her ill father at age 12 in Plains, Georgia—sparked a lifelong commitment to family caregivers and shaped the vision behind the Rosalynn Carter Institute for Caregivers (RCI).

We define family caregivers as those caring for someone who is aging, ill, or living with a disability. This includes care provided by spouses, children, parents, friends, and extended family—often unpaid and unrecognized. Learn more about who we consider a caregiver here: <https://rosalynncarter.org/caregiver-profiles/>.

For nearly 40 years, RCI has worked to ensure caregivers are visible, valued, and supported. Our approach is shaped by experiences and data-backed insight, and it's rooted in the understanding that caregivers' roles are essential to the health and wellbeing of families and communities.

### Through our commitment to inclusion, we:



**See Caregivers** — Bring visibility to caregiver experiences and the essential work they do, often without formal recognition.



**Hear Caregivers** — Listen deeply and respectfully to the stories caregivers choose to share, honoring their voices and allowing their insights to guide the design of more responsive support.



**Support Caregivers** — Create impactful programs, resources, tools, and policies that drive real change, grounded in data and action-oriented engagement.

Over time, RCI's evolving mission and research methods have illuminated critical gaps in our collective understanding of caregiving. Data drawn from RCI's long-standing programs provide context on the experiences of caregivers—shaped by factors like financial stability, work-life balance, culture, race and ethnicity, family structure, stress levels, and both physical and mental health.

# Who We Are:

## Evidence and Impact First



Founded in 1987, RCI has been dedicated to improving the lives of family caregivers and promoting a better understanding of their critical role in the health and care system. **RCI is one of the first organizations to consistently develop programs built on evidence, using a data-driven approach that employs statistically significant analysis.** At the core of who we are is a deep commitment to understanding what works, how to scale it, and why it matters—through research, resources, policy, and advocacy.

## How Do We Do It?

We begin with **systematic surveys**, listening to caregivers' challenges and experiences. Then we **translate these insights** into responsive, scalable solutions. After implementation, we follow up to better understand what's changed, where more support is needed, and how our tools perform across diverse populations. This feedback loop ensures caregivers and those who support them receive effective solutions tailored to their needs and realities.

RCI also clarifies the often-overlooked impact of caregiving by capturing and analyzing real-world outcomes. These insights have shaped a foundation of actionable, responsive programs and tools that improve the lives of caregivers and their families.

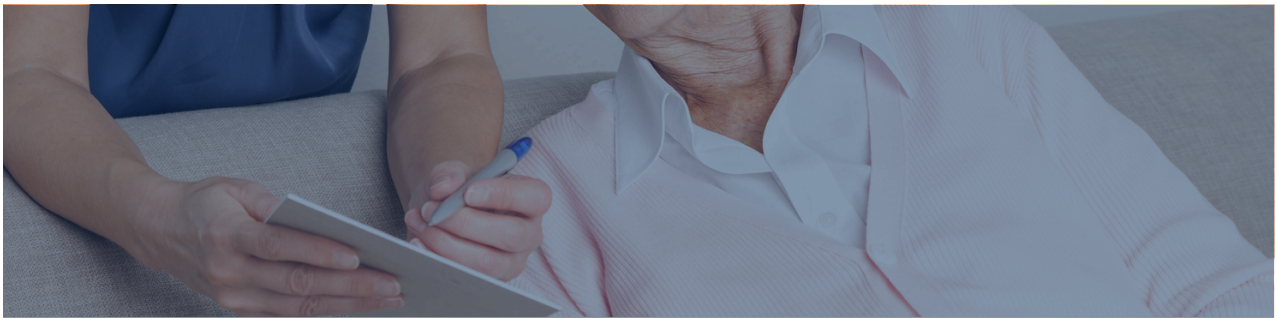
## 30 Years and Counting: RCI's Evidence-based, Data-driven Systematic Approach

The growing awareness of caregiving and its complexity has increased the urgency to share what works. RCI's decades of investment in data and evaluation allow us to better address the needs of today's caregivers and quickly scale programs for broader impact. For over three decades, RCI has built a base of validated knowledge through both internal and external research that helps advance the field.



## Evidence Validated in Publications Increases Credibility and Access

RCI shares findings in peer-reviewed journals and widely trusted publications, ensuring greater reach and adoption. Publications include **Public Policy & Aging Report**, **Library of Medicine**, and **Sage Journals**. Former First Lady Rosalynn Carter's groundbreaking 1995 book, *Helping Yourself Help Others*, was reissued in 2013, with updates from former CEO Jennifer Olsen and interim CEO Paurvi Bhatt to reflect a new chapter of national leadership.



"Since RCI's founding in 1987, the organization has worked to promote the health, strength, and resilience of caregivers. RCI has advocated on behalf of caregivers and testified to Congress on behalf of relevant policies. In its papers and surveys, RCI has introduced new data highlighting the impact of caregiving on mental health, employment, and public health."



A key framework that summarizes RCI's approach to program design and evaluation was developed through a partnership with Duke University in the study "Individual and Program Characteristics May Drive Variability in Outcomes After Caregivers Participate in a Tailored Support Intervention," published in the *Journal of Applied Gerontology* in 2022.

*(Note: RCI REACH is also among our earliest evidence-based programs, anchoring this legacy of rigorous evaluation.)*

# RCI Conceptual Framework

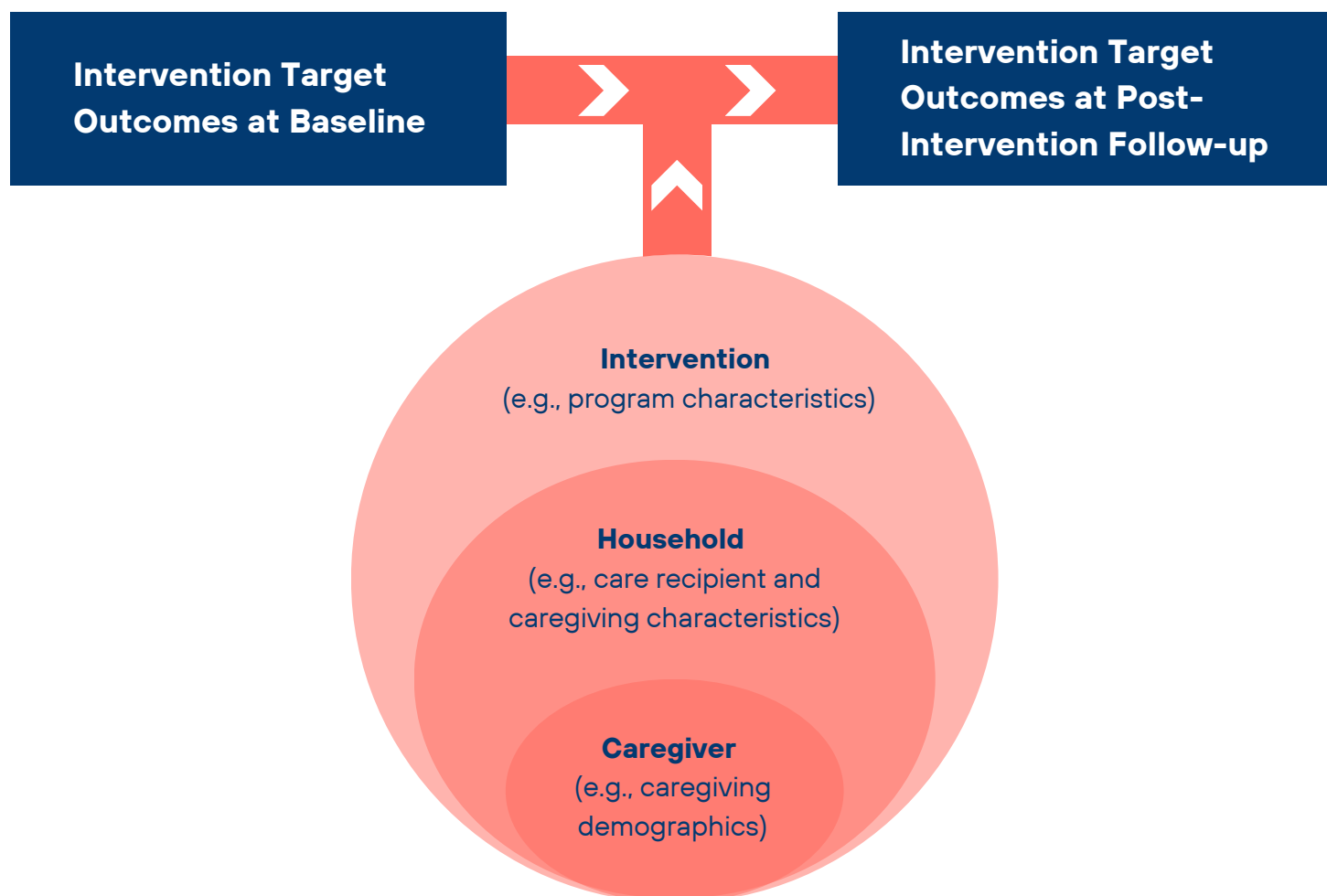
## Driving Our Impact

Based on early insights with military caregivers, RCI examined 21 variables at the individual, household, and program levels using elastic net regression to pinpoint the drivers of meaningful improvement. These insights help sharpen program design so that solutions are not just well-intentioned but work for caregivers in real-world conditions.

By connecting these frameworks with evaluation and review, RCI translates **research into actionable improvements** that directly benefit caregivers' daily lives.

**This framework provides the key factors that program designers and implementers need to consider when they either design or implement caregiver support interventions.**

**Figure 1. RCI Conceptual Model of Potential Drivers that Change Outcome**





# Who We Serve:

## Context Matters



Based on a 2024 [Rand study](#), **105.6 million Americans** are caregivers, making up **40.5% of the U.S. population**, with unpaid labor valued at over **\$600 billion annually**. Our research is drawn from diverse communities—including Hispanic and African American caregivers, military families, youth caregivers, and caregivers living in rural areas.

Over 20 years of data confirm that caregivers frequently face **isolation, financial strain, and mental health challenges**, as seen in RCI program data. To better understand and respond to these needs, RCI examines how identity and context shape caregiving experience.

### Location matters: Rural Caregivers

- **Rural caregivers** face significantly limited access to resources and support.
- Rural caregivers report significantly higher financial stress than urban caregivers.
- Rural caregivers show greater self-efficacy and dementia knowledge than urban peers.
- They also receive **less public support** compared to urban caregivers.

### Caregiver Age: Youth to Older Caregivers

- **Older military caregivers** report significantly lower satisfaction with life than younger ones.
- **Youth caregivers** often juggle school and caregiving responsibilities (Journal of Adolescent Health, 2024).
- *RCI data further shows:*
  - The **older the caregiver**, the less financial stress and the lower family-to-work conflict.
  - The **younger the caregiver**, the more caregiving confidence and dementia knowledge.
  - Younger caregivers report greater decreases in caregiver depressive symptoms and dual-role stress.



## Women, Gender, and Caregiving

- **80% of RCI program participants are women**, with 47% working full-time while caregiving.
- 97% of texters using RCI's Crisis Text Line with code "TOUGH" were women, showing higher emotional distress.
- Women caregivers report **higher dementia knowledge** than men and more active information-seeking.
- Despite this, the **perceived financial stress** of women caregivers is significantly higher than male caregivers.

## Caregiver Race and Ethnicity

- **Hispanic caregivers** report significantly higher perceived financial stress and work-to-family conflict compared to non-Hispanic caregivers, despite equal satisfaction with care work.
- **African American military caregivers** show more effective problem-solving and coping skills.
- **African American caregivers** overall experience more depressive symptoms and burden than their white peers.

## Education Level and Caregiving Experience

- The **higher a caregiver's education level**, the lower their satisfaction with the caregiving role.
- The **higher the education level**, the more dementia knowledge caregivers demonstrate.

## Employed Caregivers

- **1 in 5 employees** is a caregiver (RCI National Survey Report, 2021).
- Caregiver employees miss an average of **3.2 workdays per month** (RCI National Survey Report, 2021).
- **1 in 3** have had to leave a **job** because of caregiving responsibilities (RCI National Survey Report, 2021)..



# What We Do:

## Programs Delivering Change and Impact



Our approach has always involved engaging caregivers directly, listening, shaping solutions with them, testing approaches, capturing results, and positioning for scale. To do this well and responsibly, we've grounded every step in rigorous research and evaluation. What have we learned? RCI program data shows:

- **When women caregivers** focusing on dementia participate in RCI programs, their confidence and dementia knowledge improve more than any other group.
- **Community connection matters**—when social ties are maintained and not disrupted during caregiving, loneliness and depression decline.
- **Family caregivers consistently report reductions in loneliness and depression** when participating in RCI programs, compared to episodic support.
- **Rural caregivers** demonstrate greater gains in self-efficacy and dementia knowledge than urban caregivers, particularly when interventions are tailored.
- **Employed caregivers** benefit from targeted interventions that help balance caregiving and work responsibilities.
- When **caregiver depression symptoms decrease**, so does child anxiety—suggesting caregiver wellness may have ripple effects across the household.
- **Younger caregivers** report greater decreases in caregiver depressive symptoms and family-to-work conflict. They often alleviate stress by building skills earlier and applying them across dual responsibilities.

**We've also prioritized national collaboration and innovation to help caregivers prepare for emergencies:**

- **A first-of-its-kind Preparedness Guide**, developed in collaboration with FEMA, equips caregivers with guidance to keep loved ones safe in the event of disaster. (FEMA + RCI, 2024)
- RCI's new Data Platform centers on three core pillars: our data, external research, and caregivers' perspectives. Using data from multiple systems and sectors, we can uncover actionable insights that strengthen outcomes and scale solutions—within RCI and across the care economy. (Rosalynn Carter Institute, 2024.)

## Key Examples of RCI's Programs' Impact

RCI's programming reflects deep appreciation for the interconnected nature of caregiving. We design scalable, research-backed solutions that adapt to diverse realities—from dementia care to youth and veteran support to employer policies. Here's a snapshot of our programs' impact over the last decade:

**Figure 2. Snapshot of RCI's Programs' Impact from 2014 to 2024**

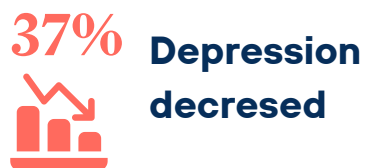
| Caregiver Population Reached     | Impact & Outcomes Achieved  | Location                          |
|----------------------------------|---|-----------------------------------|
| Dementia Caregivers              | <div> <div>22%↑</div> <div>In self-efficacy</div> </div> <div> <div>29%↑</div> <div>In dementia knowledge</div> </div> <div> <div>37%↓</div> <div>In depressive symptoms</div> </div> <div> <div>23%↓</div> <div>In subjective burden</div> </div> <div> <div>22%↓</div> <div>In family-to-work conflict</div> </div> | National<br>In person/<br>virtual |
| Military & Veteran Caregivers    | <div> <div>29%↑</div> <div>In work satisfaction</div> </div> <div> <div>32%↓</div> <div>In depressive symptoms</div> </div> <div> <div>21%↓</div> <div>In subjective burden</div> </div>  | National<br>In person/<br>virtual |
| Rural Caregivers                 | <div> <div>↑</div> <div>Greater self-efficacy dementia knowledge gains than urban peers after intervention</div> </div>   | National                          |
| Youth Caregivers                 | <div> <div>276↑</div> <div>scholarships awarded</div> </div> <div> <div>709+↑</div> <div>youth reached via school programming</div> </div>  | Georgia<br>In person              |
| Building partnerships for policy | <div> <div>167↑</div> <div>organizations mobilized to advocate for an Office of Caregiver Health</div> </div>   | National<br>In person/<br>virtual |



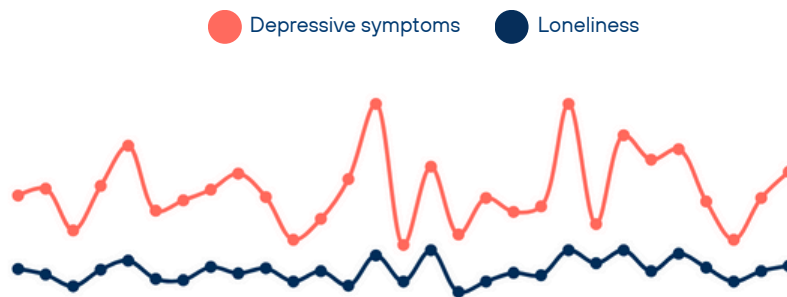


# Caregivers Empowered

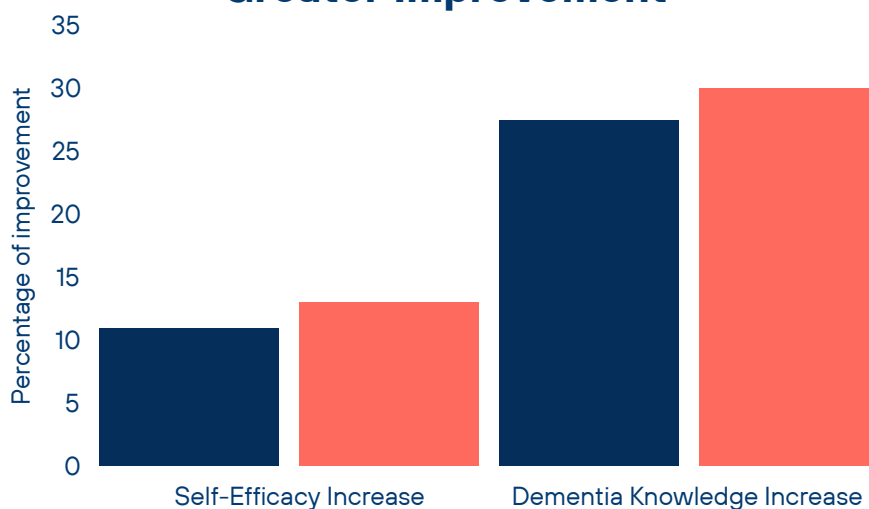
Served Tens of Thousands of Caregivers from ALL 50 States  
and Puerto Rico



## Caregiver depressive symptoms are correlated with caregiver loneliness



## Rural Caregivers Showed Greater Improvement



# How We Work:

## Cross Sector Partnerships



## Partnerships are Important Strategies that Amplify Messages to Multiple Constituencies.

RCI is recognized as a trusted leader in caregiving because of its rigorous research foundation. By collecting meaningful data and conducting thorough analysis, RCI has built credibility and earned a seat at the table. This trust enables RCI to bring together powerful coalitions across government agencies, corporations, advocacy groups, and community organizations to drive real change. These partnerships result in meaningful policy improvements and funding reforms that address caregivers' most pressing challenges.

In partnership with **Duke University**, RCI pioneered the **Profiles in Caring** framework, which outlines ten **distinct caregiving phases** and enables the delivery of **customized support at each stage of a caregiver's journey**.



RCI collaborates with veteran and military organizations such as the Elizabeth Dole Foundation, Blue Star Families, Veterans Administration, and the Wounded Warrior Project to deepen its impact. RCI also partners with organizations like Sesame Street and the National Park Service to help children understand the importance of caregiving. Additionally, RCI supports the John and Betty Pope Caregivers Scholarship at Georgia Southwestern State University—one of the first scholarships in the state dedicated to supporting current and future caregivers pursuing higher education.



# What's Next:

## Why It Matters



## Working on Caregiving for the Long Term: Our Focus Over Time Matters

Strong caregivers build stronger families, healthier communities, and a more resilient society. RCI's decades of data demonstrate what works—and why. With continued support, we can keep evolving to ensure every caregiver is **seen, heard, and supported**.

### Caregivers

Access resources, education,  
and community support.

### Policymakers

Collaborate with RCI to drive  
policy change.

### Family, Donors, Supporters

Invest in scalable, data-driven  
programs that make a lasting  
impact.

### For Healthcare, Community Organizations, And Corporate Partners

Integrate caregiver-friendly policies  
and workplace solutions.

**Learn more:**

[rosalynncarter.org](https://rosalynncarter.org)



*Read our other impact papers here:*

**Rural Caregivers**

**The Power of  
Evidence**

**Youth Caregivers**

**Understanding  
Inclusion with Data**

# References: 30 years of evidence - RCI Publications and Peer-reviewed Research Papers (1995 – 2025)

## 2025:

- [Caregiver Support Program May Decrease Work-Family Conflict: An Intervention Study](#)

## 2024:

- [Employed Family Caregivers, Time, and Community-Based Support Policy](#)
- [Health-related Quality of Life and Bereavement in the 2019 Georgia Behavioral Risk Factor Surveillance System](#)
- [An Overview of Bereavement and Grief Services in the United States](#)
- [Working While Caring: Innovations and Interventions to Support Caregivers in the Workplace](#)

## 2023:

- [Estimating Prevalence of Bereavement, Its Contribution to Risk for Binge Drinking, and Other High-Risk Health States in a State Population Survey, 2019 Georgia Behavioral Risk Factor Surveillance Survey](#)
- [Measuring Bereavement Prevalence in a Complex Sampling Survey: The 2019 Georgia Behavioral Risk Factor Surveillance System \(BRFSS\)](#)
- [The Caregiving System We Want begins with Supporting Caregivers](#)

## 2022:

- [Individual and Program Characteristics May Drive Variability in Outcomes After Caregivers Participate in a Tailored Support Intervention](#)
- [Invisible Overtime: What Employers Need to Know About Caregivers](#)
- [Prioritizing Support Offered to Caregivers by Examining the Status Quo and Opportunities for Enhancement When Using Web-Based Self-reported Health Questionnaires: Descriptive Qualitative Study](#)
- [Caregiving in US Gulf States During Natural Disasters and COVID-19](#)

## 2021:

- [Caregiving in Military Families: 2020 Military Family Lifestyle Survey Special Report](#)
- [Working While Caring: A National Survey of Caregiver Stress in the U.S. Workforces](#)

## 2020:

- [Mechanisms Through Which a Family Caregiver Coaching Intervention Might Reduce Anxiety Among Children in Military Households](#)

## 2019:

- [External Validity of the New York University Caregiver Intervention: Key Caregiver Outcomes Across Multiple Demonstration Projects](#)
- [Increasing self-efficacy and knowledge in carer training: Hispanic versus Caucasian](#)

## 2018:

- [Comparison of African American and Caucasian Caregiver Self-Efficacy](#)
- [Operation family caregiver: Problem-solving training for military caregivers in a community setting](#)

**2017:**

- Implementing evidence-based interventions the development of RCI REACH

**2013:**

- A Rural Community Translation of a Dementia Caregiving Intervention

**2010:**

- Evidence-Based Practices and the Rosalynn Carter Institute

**2006:**

- "Caring for You, Caring for Me": A Ten-Year Caregiver Educational Initiative of the Rosalynn Carter Institute for Human Development

**2004:**

- A commitment to professional caregivers: the Rosalynn Carter Institute for Human Development

**1999:**

- Helping Someone with Mental Illness

**1995:**

- Helping Yourself Help Others: A Book for Caregivers.

***The Rosalynn Carter Institute for Caregivers is the nation's leading authority on evidence-based caregiving support, advocating family caregivers in the United States.***